LEARNING TO DIE*

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DEATH and dying among the aged presents a paradox. Disease and death are the traditional enemies of physicians. But among the elderly disease is usual and death is not only inevitable but often welcome. What frequently concerns older patients is being disabled, being a burden—the *quality* of their dying. Thus, the aged seem to demand a separate ethic, a different philosophy of medicine.

Yet I think it is not the aged who create the problem. Rather it is our present medical ethic that is at fault. Our problem with the aged only sheds light on that fault.

It seems never to have been fashionable to discuss philosophy and medicine in the same context. Nonetheless, medicine does rest on a philosophical base—a set of first principles that determines the way we do things.

The principles that particularly apply to medicine include a belief in the sanctity of life and a belief in the value of reason in discovering order in the universe.[1] The belief in the sanctity of life has been translated into the medical ethic of protecting life and averting death as far as ability extends. The belief in the value of reason in discovering order in empirical facts is the basis of our faith in science. The basic articles of faith, then, are that the enemy is death and the weapon is science. Together they form the ethic and the mode.

The implications for the aged of the ethic to extend life are obvious and profound. It is the basic reason that there are so many old people, but it is also the reason that so many have lost the meaning of life in the pursuit of staying alive.

It was not always so. The Hippocratic Oath does not mention such an ethic, but rather tells us to benefit our patients and to abstain from the harmful.

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An ethic that requires benefit and no harm is not at all the same as the ethic to preserve life at all costs. Indeed, it is the perversion of "do benefit but no harm" into "preserve life at all costs" that has gotten us into trouble—and not solely in the care of the aged.

Believing that the primary mission of physicians is to preserve life at all costs is harmful in several interrelated ways. It deprives us of the meaning of a human being as a person, focuses the physician exclusively on the body as a machine, and denies us the uses and meanings of our own deaths. Profound problems arise for society when considerations of a human being as a "person" and the utility of death for life are excluded from the operating purview of doctors.

Two characteristics of scientific thought seem to lie at the base of our difficulty. The first troublesome characteristic of science is that it deals with the material and the universal—stopping at the border of the individual. The second troublesome characteristic is the confusion of structure for function. Both of these have a history and both of them require some comment.

Attempts to define himself seem to have arisen with man. These attempts have given rise to religions, philosophies, and even science. But understanding what makes man more than an animated body continues to elude him.

Now, more than 300 years into the scientific era, we view a marvelously ordered universe with a system of thought that has revealed its secrets, unfolding as the succeeding pages of a book. And still the nature of person is a mystery.

Little wonder that the aged trouble us. When we view a group of young people with pleasure we see an aliveness and joy, a magic vitality that is as much a flowering of the body as the person within. But when we find special pleasure in an old person, even in his looks, it is the person shining through; the body is secondary. We appreciate the rareness of success in age. We wonder how the old man did it and wish ourselves the same reward.

A person who succeeds in living well in old age has done something to himself, with himself, that has made the difference. Those same old people frequently deal with the infirmities of their bodies and handle illness and disability better than most of their contemporaries. Often, and still harder to understand, the successful older person may manage his death with the same dignity and meaning as his life. What did he

do and how was it done? How did such a person come to be?

It is striking how little science has told us of these things. The point is made clearer by recognizing that if one is interested in exploring the meaning of person and inner growth one reads philosophy, not science, and seeks help as much from the ancients as the moderns.

For the care of the aged, or anyone, these questions are vital. But despite the inherent interest of these matters, they have not been in the limelight. There are reasons for the vacuum of science here that are also significant for other facets of the human condition.

One reason is that the meaning of person and the nature of inner growth are personal matters—personal things, if you will—which, even though they are universal, are at the same time individual. Individuality seems to defy the tools of science because an individual is a value-laden object not well described simply by a list of the facts of his existence. Science as a descriptive discipline is based on the pursuit of facts, and the utility of those facts lies in their generalization beyond the particular. Values, represented here by words such as serenity or dignity, seem to impede generalization because of their apparently fluid nature. Or at least that is a common belief. Science, as the pursuit of the cause of things, is conceived as being similarly impeded when the facts with which it works are not value-free, while the basic problems we have identified in understanding the aged, the meaning of person, and the nature of inner growth are value-laden, personal, and individual.

Over the past few centuries, but particularly in the last 100 years or so, our culture has increasingly depended on science to solve its problems. But, as we have seen, it is in the nature of that system of analytic reasoning to be exterior to the individual, to the personal, seeking causes and solutions in the material or the universal—in the world outside each man—seeing forces as acting on man from outside rather than arising from within him. In our culture, we frequently think this way about our world. When we see a human problem we attempt to solve it by making something act on people from the outside, whether the acting force be education or penicillin. That method of problem solving has been extremely useful, but it has its limitations. In considering death and dying among the aged those limitations are most painful.

As physicians, that method of problem solving is translated into caring for a body—making it well by doing something to it. We strengthen the failing heart with digitalis, quiet the painful joint with anti-inflammatories, lift the blanket of depression with drugs, give

antimicrobials for infection, antihypertensives for hypertension, and so on. This approach, though often effective, sometimes dramatically so, is still a losing battle in the face of encroaching age. Aging does not conform to our basic model of disease, which has an onset, course, and termination. Aging starts at birth, its course is life, and its termination death. We are at the same time spectators and participants trying to affect the aging process piecemeal but always external to it.

Experience shows us that those who age well somehow have a different relation to their bodies. The patient's relation to his own body is as important as the success of our drugs. Yet we do not know what that means or how to influence it. We are left dealing with the body as though it were a machine—doing something or not doing something to it. It does not occur to us that forces for solution may reside within our patients. We have forgotten, in this age of cure, that the relation of a person to his body, deep within, is also within our province.

To summarize thus far, first it is clear that our present ethic, to preserve life, is a perversion of the older and more basic ethic, to do benefit. The ethic to save life is a body ethic, an objective matter, but benefit is a value-laden word derived from the meaning of person—a personal or private matter.

Second, when we seek guidance for our problem from the rational, analytic thought of science, we receive little help. That kind of thought seems to be found wanting because it stops short of the border of the personal, the individual, or the moral. Within those borders lies our problem, because in no other way but the personal and individual will we be able to help our patients with the final burden of aging: their own dying and death. In stopping where it does, science as a way of thought has convinced us that the solutions to our problems lie outside of us, in things being done to us rather than coming from within us.

The prevailing solution to the problem of defining person is an ever closer look at the molecular biology of behavior, memory, anger, and so forth. Still, we get no closer to the meaning of person as the watchmaker who knows ever more about the watch but is brought no closer to the meaning of time.

A second troublesome characteristic of science in medicine is the confusion of structure for function. The great advances in medicine have been heralded by discoveries of the structure of the body: first anatomy, then pathologic anatomy and, most recently, biochemical structure. We define diseases in structural terms—anatomically or bio-

chemically, but nonetheless structurally. The tumors, arthritides, diseases of the heart, liver, etc. are classified and distinguished in structural or biochemical terms. We are all aware of the importance of nosology to medical progress in allowing us to define our terms in the search for cause and cure. As Claude Levi-Strauss[2] has made clear, we share with primitive man the need to classify and schematize and, as for primitive man, our world has been given order by our efforts. But, as useful as the system as been, it has serious flaws in understanding the sick; these flaws are most obvious in the care of the aged.

When we define in structural terms we are often led away from an understanding of process and function. I once saw an older patient with rheumatoid spondylitis. Characteristically unable to straighten up, his x rays demonstrated severe, classic disease. In a hypnotic trance he was able to straighten 25% more than he had ever been able to do. No magic was involved. In the trance, the muscle spasm associated with the diseased spine was relieved and his mobility increased.* It was suddenly clear to me how inadequate a purely structural understanding of rheumatoid arthritis was for understanding and managing a patient with the disease. Similarly narrow is the conception of coronary heart disease in terms of vessels narrowed by atherosclerosis. We are all aware that some patients with minimal stenosis have infarctions and some with widespread atherosclerosis are without apparent limitations. To explain these discrepancies, biochemical explanations have been offered. These also are inadequate by themselves; to be understood, the heart must be seen as the dynamic, changing, object-in-motion that it is. But for that purpose our language seems inadequate and thinking difficult. Dr. Howard Rusk brought the meaning of functional thinking into our midst with rehabilitation medicine but, sadly, we see second-generation practitioners dealing with "activities-of-daily-living" as though that were some new kind of fixed structure. In the end we fail to see process and function because we have no suitable language. (There may be no language of process except poetry, but it will be some time before poetry replaces statistics as the language of science.)

Structural explanations of disease are especially inadequate in caring for the aged. The old are often walking textbooks of pathology. Sometimes they feel and function well, and at other times older people are disabled. Sometimes, when treating a disease, we create more disability than existed previously.

*I am indebted to Dr. Hans Kraus for the demonstration and for sharing his great understanding of the process.

We find ourselves increasingly looking to the person inside the aged body in order to understand these discrepancies of disease and disability. But, as noted earlier, our science is inadequate for an understanding of the personal or the individual. Thus our failures with the aged have exposed the weakness of our ethic and the inadequacies of our science.

The effort to save life at all costs has not only in many instances made a mockery of life, it has stolen from us the utility and meaning of death. Death needs to be an intimate part of living, not as an object of fear, but as a symbol of life—not in any depressing sense, but as a goad to creativity and a reminder to fill life with meaning. Finally, when further creativity is impossible and love and meaning are past recall, death should be seen as a welcome friend.

What are we to do with the aged until the next scientific revolution gives us a language of process and an understanding of person?

We do what physicians have always done when concepts fail: we go back to our patients. We try with all our power to shed preconceptions and listen, really listen. To do that with the aged, absolute honesty is required—not honesty of words such as cancer or death, which in any case mean more than they say, but honesty of feelings. In return for our honesty patients will be honest with us. Neither they nor we may understand what they are saying, it may not even be in words, but it will be there to think about. When that happens, exciting things emerge. We shall see, deep inside, the relation of person to body and the therapeutic power in that relation. The nature of process will become clearer. If it sounds mysterious it is only because we do not yet have the language. But while the language may be necessary to teach someone else, it is not necessary for teaching oneself.

Let me be more explicit. Much evidence points to the fact that death is not always a mechanical event or easily explained in terms of disease. Death by exorcism and the casting of spells—voodoo death—is one documented example.

Less dramatic but more common are those cases in which persons are said to die of grief or, as in the well-known phenomenon of elderly couples, where the death of one follows closely the death of the other.

Further, experienced physicians know that some die in apparently greater distress than others and the differences are poorly explained in physical terms. Kubler-Ross speaks of leading patients through stages of dying, the last being acceptance where death comes more easily.[3] St. Christopher's Hospice in London is devoted to the care of the dying in an active, not passive, sense.[4]

All this tells us that, in clinical terms, in terms of caring for patients, death is a process, not merely an event. Seeing the dying patient as a passive object being dragged to his death by disease or age, much as the wind tosses leaves, is a failure of understanding. To regard the doctor caring for the dying as one who, with technology, tries to retard, or even to speed, the inevitable, is to share that failure. These failures of understanding arise from present-day thought placing understanding of the universe exterior to the individual.

If death is a process in which the dying person plays a part, no matter how little understood, then it is a process in which we can offer concrete help.

We spend our lives fighting sickness, regression, disability, and death. Physicians spend their lives in the service of that fight, exhorting and abetting the will to live, the life force. Call it what you will, measurable or not, we know that the life force exists and that it is potent. But there is a time to stop—not merely to stop the application of technology but to actively help the dying patient develop the will to die.

This can be done with the very ill and the aged, in the most practical terms. It is possible to suggest to the patient that the time has come to leave. But at the same time it is necessary to reassure the patient that it is all right to leave and that it is not going to hurt. We are all afraid of unknown pain, but things rarely hurt as much as we thought they were going to. When one explains this to a patient, one is amazed to discover that the patient becomes more peaceful and that pain, if present, becomes less severe and more bearable, and that within a relatively short time the patient dies. Sometimes teaching the aged how to die turns into teaching the dying how to live.

A case may illustrate. A 78-year-old woman had a biopsy diagnosis of carcinoma of the esophagus made three months earlier. She had received appropriate cobalt radiation and remained essentially free of symptoms until about three weeks before being seen. At that time she began to have increasing pain and inability to swallow and an x ray was said to indicate tracheoesophageal fistula. When she was admitted to the hospital she did not have the appearance of a dying person, but our x rays, while they did not confirm the fistula, revealed the far-advanced state of her disease. All she could expect was ever-increasing pain and gradual starvation.

She had been told little else than that she had a tumor. Consultation with surgeons and other physicians supported the conclusion that there was virtually nothing to offer that would do more than briefly pro-

long her life—a painful life at that. The family, stating that she had always been a strong-willed, independent, and dignified person, were against any life-prolonging heroics. All this was noted on the chart.

I had a long conversation with the patient. I said that I could do nothing further for her tumor, which would continue to grow. However, most of my statement was positive; she was told that she had much more power over her own body than she knew and that I would support her in whatever she decided to do. I made it clear that there was nothing to be frightened of, that everything would be done to make sure she had as little pain or distress as possible. Three aspects were emphasized. The disease could not be cured. She had more control over the situation that she knew and would be supported in whatever course she decided to follow. She was not to be frightened, because pain and distress could and would be controlled. The following day she said "I guess you said I have to learn to live with it." I agreed and again emphasized the amount of control she had and that she should not be afraid of pain.

The next day she developed fever, and died eight days later of untreated pneumococcal septicemia. Throughout her brief terminal illness she was quite comfortable, requiring less medication for pain than expected. On each visit, support and freedom from fear and pain were underlined. No hope of cure was extended but, curiously, hope itself was maintained. Our relation seemed good. In the last few days her consciousness became clouded and she died in coma.

It must be emphasized that the psychological pattern that was developed in the care of this woman was very different from that ordinarily provided. Although her impending death and cancer were not specifically discussed, she was not exhorted to "fight" or get better and the future was not discussed by me. Emphasis on getting better and on the future are so much a part of the usual framework of medical care that they have become invisible. Consciously changing the mental pattern is difficult, since every word and action must be monitored.

Changing the pattern is the equivalent of changing the most basic rules of treatment. Doing this is hard on the physician. The process strikes deep within and finds painful resonance in the doctor. It is difficult to find the proper words and yet absolute honesty is required. The doctor must openly face his responsibility. He must be right, in the light of his knowledge and judgment, that indeed the time has come for the patient to leave.

The process is based on trust. The patient is being told that it is per-

missable, indeed necessary, to stop doing something that he has done his whole life: namely, battle for life, and he is being told that it will not hurt. To accept that assurance requires a deep trust of one human for another.

In addition to the patient's trust, the ability of the physician to help the patient die comes from a part of his general function: the giving of permission. The social scientists have pointed out that physicians validate their patients' illnesses for society. But they fail to see the constant battle between self and body, between pain and will, that takes place in illness. The disease may be the cause and the social setting may be the stage, but the battle is in the person. It is the physician who gives permission for the person, when he becomes ill, to stop and do battle for his body. And, once health has returned, it is the physician who gives permission once again to get on with life without fear of or for the body. In the case of the dying, based on trust and the service of his patient, the physician can give permission for the person to stop the battle for life.

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